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ABSTRACT

This research analyzes similarities and differences in how students with disabilities are identified in national databases, through examination of 19 national data collection programs in the U.S. Departments of Education, Commerce, Justice, and Health and Human Services, as well as databases from the National Science Foundation. The study found that significant variability was evident in the disability categories used both within and across the national data collection programs. The variability was found in the use of terms that corresponded to the federal categories of seriously emotionally disturbed, hard of hearing, deaf, visually handicapped, orthopedically impaired, and other health impaired. The disability category for which there was the greatest similarity of terms across the largest number of data collection programs was speech impaired. Suggestions are provided for improving disability identification in collecting and reporting policy-relevant information. Appendixes provide tables indicating correspondence among federal disability categories and categories used in national data collection programs, and outlines examples of new variables to be considered to better describe those individuals who are included or excluded in data collection programs. (Contains 13 references.) (JDD)

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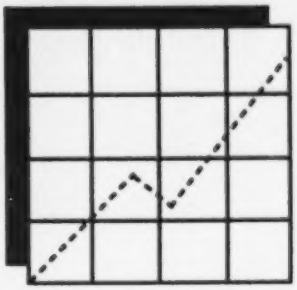

The Identification of People With Disabilities in National Databases: A Failure to Communicate

National Center on Educational Outcomes

The College of Education
UNIVERSITY OF MINNESOTA

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in collaboration with

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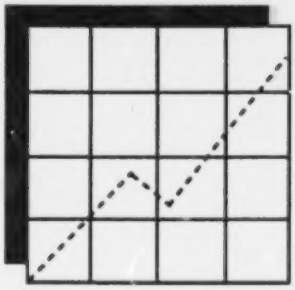

The Identification of People With Disabilities in National Databases: A Failure to Communicate

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National Center on Educational Outcomes

The College of Education
UNIVERSITY OF MINNESOTA

September, 1993

The National Center on Educational Outcomes (NCEO), established in 1990, works with state departments of education, national policy-making groups, and others to facilitate and enrich the development and use of indicators of educational outcomes for students with disabilities. It is believed that responsible use of such indicators will enable students with disabilities to achieve better results from their educational experiences. The Center represents a coliaborative effort of the University of Minnesota, the National Association of State Directors of Special Education, and St. Cloud State University.

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Abstract

In an era of significant rhetoric and action characterized as "education reform," words and phrases like "full-inclusion," "inclusionary practices," and "equity" have become battle cries for professionals who want all students included when educational policies and practices are developed. Recently, concern is being expressed about the exclusion of students with disabilities, students from disadvantaged backgrounds, and students from different cultures from assessments and other activities related to educational outcomes. Findings that significant numbers of students with limited English proficiency and disabilities are not included in state reports of pupil performance or in national data bases have added to the urgency of these concerns and provided impetus for continuing study. The purpose of this research was to analyze similarities and differences in how students with disabilities are identified in national data bases. We examined 19 national data collection programs in the U.S. Departments of Education, Commerce, Justice, and Health and Human Services, as well as data bases from the National Science Foundation. Significant variability was evident in the disability categories used both within and across the national data collection programs. Suggestions are provided for improving disability identification in collecting and reporting policy relevant information.

The Identification of People With Disabilities in National Data Bases: A Failure To Communicate

Calls for reform in American education during the past decade have resulted in raised expectations, attempts to develop uniform and "world class" standards, increased emphasis on school accountability, and heightened interest in the measurement of school outcomes. Reform initiatives at national, state, and local levels are focusing more frequently on the products as well as the processes of schooling. As professionals seek to produce policy-relevant information on the educational performance and status of children in our nation's schools, the search for indicators of success is playing a central role in reform activities. National and state data bases are being used as a basis for monitoring and evaluating the effects of these reform initiatives (McGrew, Spiegel, Thurlow, Ysseldyke, Bruininks, & Shriner, 1992).

Efforts to assess educational progress flourish in eras of reform and innovation. Probably no single factor has pushed current accountability efforts more than activities that surround the six national education goals and the National Education Goals Panel (NEGP) that monitors them. Since the time the goals were endorsed by President Bush and the nation's governors, a flurry of state and federal activity has focused on identifying indicators of progress toward the national education goals. Developing indicator systems has become big business in the United States (Odden, 1990), with nearly all national and state education agencies becoming more involved in decision-making, monitoring, accountability, and measuring educational progress than ever before in the nation's history (McGrew, Thurlow, Shriner, & Spiegel, 1992). Even a cursory review of the educational reform literature leads to the conclusion that there is a hunger for policy-relevant information on the performance of students in our educational system.

The United States has a developing and rich tradition of assessing student progress as a measure of the overall quality of its education system (McGrew, Thurlow et al., 1992). Scores on cumulative tests (generally standardized) administered at selected school transition points (e.g., graduation, promotion to third grade) serve as data for decision-making and documentation of the need for improvements and programs. National data collection programs such as the National Assessment of Educational Progress (NAEP), often called the "Nation's Report Card," the National Longitudinal Study (NLS), High School and Beyond (HSB), and the National Education Longitudinal Study (NELS) are a few examples of recent and continuing efforts to provide periodic data on the educational status of America's school children.

In an era of significant rhetoric and action characterized as "education reform," the terms "full-inclusion," "inclusionary practices," and "equity" have become commonly used phrases for highlighting the need not to exclude students with disabilities and students from disadvantaged backgrounds and different cultures when producing educationally relevant policy reports. Though not a new idea, the practice of including <u>all</u> students in educational experiences available to <u>any</u> students has recently had an impact on personnel concerned with assessment and educational outcomes. Findings that significant numbers of students with limited English proficiency and students with disabilities are not included in state reports of pupil performance and national data bases have added to the urgency of these concerns (Ingels, 1991; McGrew, Thurlow et al., 1992; Spencer, 1991).

Excluding students from any national, state, or local sources of data causes serious concerns when compiling, reporting, and interpreting scores; including students using different definitions or methods for grouping and describing them also causes problems (Algozzine, 1992). Under conditions of national importance, policy decisions should be made on the basis of consistent information with known characteristics.

The purpose of this paper is to describe similarities and differences that exist in how subpopulations of students with disabilities are identified in national data bases and to make

suggestions for ways to improve current practice. Students with a wide array of disabilities fit within this population, including those with learning disabilities, emotional disabilities, and speech and language impairments, those with sensory disabilities such as hearing impairments and visual impairments, and those with multiple and more severe disabilities, typically involving significant mental impairments. Given that approximately 4.8 million school-age youngsters with disabilities receive some form of special education services, services that are provided at significant expense to our educational system, it is imperative that we examine how these students are performing. A recent report (McGrew, Thurlow et al., 1992) suggested that large numbers of students with disabilities are excluded from many prominent national data collection programs. In addition to the exclusion issues, the inclusion of appropriate descriptor variables in national data collection programs is a prerequisite for extracting useful policy-relevant information regarding this population. This paper describes how individuals with disabilities are currently identified in national data collection programs and makes suggestions for ways to improve current practice.

Method

Nineteen national data collection programs identified by the National Center on Educational Outcomes (NCEO) for students with disabilities were analyzed in the current investigation. These data collection programs represent a subset of 28 national data collection programs identified by the NCEO as being potentially useful in the extraction of policy-relevant information on the educational status and performance of students with disabilities (McGrew, Spiegel et al., 1992). The complete set of 28 data collection programs was targeted based on their: (1) potential usefulness in providing indicators of outcome domains in the NCEO conceptual model of educational outcomes for children and youth with disabilities (Ysseldyke, Thurlow, Bruininks, Gilman, Deno, McGrew, & Shriner, 1992), and (2) prominence in current efforts to monitor progress toward the attainment of national education goals. The list of 28 national data collection programs targeted by the NCEO is presented in Table 1.

The 19 data collection programs included in the current investigation are briefly described in Table 2 (only 18 programs are listed in Table 2; the child and adult versions of the National Household Education Survey, which is listed once, are counted as separate data collection programs due to different samples and instrumentation). These programs were selected from the set of 28 because they include important indicators of outcome domains for individuals with disabilities (e.g., National Health Interview Survey) (McGrew et al., 1992), or are highly visible programs playing a prominent role in the current wave of educational reform (e.g., Current Population Survey, National Assessment of Educational Progress). Given the prominence of the Department of Education's data collection programs in current reform activities, this Department's programs (including those of NCES) were given greater attention in this analysis. They comprise the largest number of data bases (n = 11) analyzed here. Five data collection programs were sponsored by the Department of Health and Human Services, and the remaining were sponsored by the National Science Foundation, Department of Commerce, and Department of Justice. A comprehensive "disability sensitivity review" has been completed on the 19 programs (McGrew, Spiegel et al., 1992).

An example summary of a completed disability sensitivity review for the 1988 National Assessment of Educational Progress (NAEP:88) is presented in Figure 1. Information regarding the "disability definitions and categories" (see Figure 1) used in each of the 19 data collection programs was abstracted from the completed disability sensitivity review summaries (see McGrew, Spiegel et al., 1992 for detailed disability review summaries for each data collection program). This information served as the primary data for the current investigation. A summary of the process and procedures used to obtain this information for each data set is provided in McGrew, Spiegel et al. (1992).

Table 1

Preliminary List of NCEO Targeted National Data Collection Programs

Department of Education

- Transcript Studies
- National Adult Literacy Survey
- National Assessment of Educational Progress
- National Assessment of Educational Progress: Trial State Assessment
- National Longitudinal Transition Study of Special Education Students
- National Education Longitudinal Study
- National Household Education Survey
- Young Adult Literacy Survey
- Beginning Postsecondary Students
- Baccalaureate and Beyond
- Early Childhood Longitudinal Study

Department of Commerce

- Current Population Survey
- Survey of Income and Program Participation

Department of Labor

- Workforce Participation Survey
- Workplace Literacy Assessment

Department of Justice

- National Crime Survey

Department of Health and Human Services

- National Health Interview
- National Health and Nutrition Examination Survey
- National Survey of Personal Health Practices and Consequences
- National Survey of Family Growth
- National Adolescent Student Health Survey
- Youth Risk Behavior Surveillance Survey
- National Household Survey of Drug Abuse
- Monitoring the Future

National Science Foundation

- Survey of Graduate Students and Post Doctorates
- Longitudinal Study of American Youth

American Council of Education

- General Education Development Testing

The College Board

- Advanced Placement Tests

Table 2

Descriptions of National Data Collection Programs Included in Investigation

National Adult Literacy Survey (Department of Education) - NALS:92

A nationally representative cross-sectional study designed to collect information on the types and levels of literacy skills of adults and how these skills are distributed across major subgroups. This study assessed the prose, document, and quantitative literacy of young adults in 1992.

National Assessment of Educational Progress (Department of Education) - NAEP:88
National Assessment of Educational Progress: Trial State Assessment Program (Department of Education) - TSAP:90

NAEP is a nationally representative cross-sectional study designed to monitor the knowledge, skills, understanding, and attitudes of the nation's children and youth. This data collection program began in 1969 and currently assesses different curriculum areas (e.g., reading, writing, mathematics, science, citizenship, U. S. history, geography, social studies, art, music, literature, career and occupational development) in grades 4, 8, and 12 every two years. The 1988 NAEP and the voluntary state program started in 1990 were reviewed for this report. The Trial State Assessment Program provided state-level mathematics data for eighth graders for 40 participating jurisdictions.

National Education Longitudinal Study of 1988 (Department of Education) - NELS:88

A nationally representative longitudinal study designed to assess the baseline experiences of 8th grade students and to relate these experiences to current academic achievement and to later achievement in school and life. The 1988 base year data collection program gathered data in a variety of areas such as work status, opinion values, school characteristics, school atmosphere, school work, school performance, guidance, special programs, after-school supervision, involvement with community, after-school activities, educational and occupational life goals, and financial assistance. Follow-up assessments will be completed every two years from 1990 to 1996.

National Longitudinal Transition Study of Special Education Students (Department of Education) - NLTS:87

A nationally representivative longitudinal study of special education students who were in grades 7-12 during the 1987 base year sample. By collecting a wide array of information from parents/guardians, school records, and school administrators, this data collection program provides descriptive information regarding the transition of youth with disabilities from secondary school to early adulthood, and seeks to identify factors that contribute to effective transition of youth with disabilities. The first follow-up was completed in 1990.

National Household Education Survey (Department of Education) - NHES:91

A nationally representative cross-sectional sample of households were surveyed in 1991 to provide national data regarding early and adult education issues. The 1991 base year survey targets information on the care and education of 3-to-8 year old children, and the participation of adults in education activities.

Table 2 (continued)

Young Adult Literacy Survey (Department of Education) - YALS:85

A nationally representative cross-sectional sample of young adults from age 21 to 25 who were surveyed together with the 1985 NAEP survey. The survey assessed literacy skills in order to better understand the nature and extent of literacy problems facing young adults.

1987 Transcript Study (Department of Education) - TS:87

A nationally representative cross-sectional sample of 11th grade or 17 year old students selected from the 1986 NAEP survey. The study provided information on course-taking and its relationship to the knowledge, skills, concepts, understandings, and attitudes of 11th grade students.

Beginning Postsecondary Student Longitudinal Study (Department of Education) - BPS:90

A nationally representative longitudinal sample of students who entered postsecondary education in public and private institutions in 1989-90. The base year sample was drawn from the 1990 National Postsecondary Student Aid Study (NPSAS). The study gathers information on the persistence, progress, curriculum, attainment, and outcomes from inital time of entry into postsecondary education through leaving and entering the work force. Follow-up surveys to be completed every two years until 1998.

Baccalaureate and Beyond Longitudinal Study (Department of Education) - B&B:93

A nationally representative longitudinal sample of students in private and public postsecondary education institutions drawn from the 1993 National Postsecondary Study Aid Study (NPSAS). The study addresses the issues of access and entry into graduate education and the work force, the relationship between undergraduate and graduate experiences, and the return on investment in postsecondary education.

Current Population Survey, March Supplement (Department of Commerce) - CPS

A nationally representative cross-sectional study designed to collect information on the employment situation and demographic status of the complete U. S. population (birth through adulthood). The March Supplement is specifically designed to gather data on work experience, income, noncash benefits, and population migration. Data collection in this program has been occurring annually since the 1940s.

National Health Interview Survey (Department of Health and Human Services) - NHIS:89

A nationally representative cross-sectional study designed to provide information on the health of the civilian noninstitutionalized U.S. population (birth through adulthood). This survey has been completed annually since 1957. While the same basic demographic and health-related information is collected each year, additional information on special health topics (e.g., AIDs, aging, etc.) may be covered in any one survey.

Table 2 (continued)

National Health and Nutrition Examination Survey, Epidemiologic Follow-up Study (Department of Health and Human Services) - NHEFS:86

A nationally representative longitudinal study designed to (a) provide information on the prevalence of health conditions and risk factors, (b) monitor changes over time in health, functional status, and utilization of hospitals, and (c) track the incidence of various medical conditions in the U.S. population (birth through adulthood). The base year data are drawn from the National Health and Nutrition Examination Survey 1 (NHANES 1), with follow-ups in 1982-84, 1986, 1987, and 1991.

National Survey of Family Growth (Department of Health and Human Services) - NSFG:88

A nationally representative cross-sectional sample drawn from households involved in the National Health Interview Survey (NHIS). The 1988 cycle included women from 15-44 years of age who were included in the 1986 NHIS. The study provides national data on the demographic and social factors associated with childbearing, contraception, adoptions, and maternal and child health.

National Adolescent Student Health Survey (Department of Health and Human Services) - NASHS:88

A nationally representative cross-sectional sample of 8th and 10th grade students. The study examined the health-related knowledge, practices, and attitudes of youth in the areas of AIDS, nutrition, consumer health, sexually transmitted disease, drug and alcohol use, suicide, injury prevention, and violence.

Youth Risk Behavior Survey (Department of Health and Human Services) - YRBS:90-91

A nationally representative cross-sectional sample of students in grades 9-12. As part of the Youth Risk Behavior Surveillance System (YRBSS), this study is designed to periodically (every two years) measure the prevalence of priority health-risk behaviors among the nation's youth, and to assess whether these behaviors change over time.

National Crime Survey (Department of Justice) - NCS:86-89

A nationally representative cross-sectional sample (collected on a three year cycle) of household members from age 12 and above. The study is designed to collect data on personal and household crime victimization.

Longitudinal Study of American Youth (National Science Foundation) - LSAY

A nationally representative longitudinal study of 7th and 10th graders designed to assess student attitudes toward science and mathematics as areas of study and possible career choices. Base year data collection started in 1987, with annual follow-ups.

Figure 1
Example of Completed Disability Sensitivity Review

TITLE: National Assessment of Educational Progress - 1988 (NAEP 88)

DESIGN: Cross-sectional

CONTACT: NAEP - ETS Box 2923 Princeton, NJ 08541

PURPOSE: To monitor the knowledge, skills, understanding, and attitudes of the nation's children and youth ("Nations Report Card"). To make objective data about student performance available at the national and regional levels. Key areas: instructional practices, at-risk students, teacher work-force, effective schools.

COLLECTION CYCLE: Since 1988, assesses grades 4, 8, and 12. Since 1990, every two years (different subject areas each time) - 1988, 1990, 1992, etc

SPONSOR: US Dept of Educ NCES - ETS

DATA SOURCE	Student	Teacher	School Administrator	
COLLECTION METHOD	Test/Questionnaire	Questionnaire	Questionnaire	
SAMPLE DESIGN/ DESCRIPTION	4-stage stratified probability sample. Nationally representative samples for 3 age-grade cohorts (9/4th; 13/8th; 17/12th) from public/private schools (approx. 86 % school participation). Total n=121,062 (Main samples n=87,323; Bridge samples n=33,739).	769 reading teachers of 3,901 students in 4th grade cohort (main assessment sample). 756 writing teachers of 3,570 students in 8th grade cohort (main assessment sample).	994 school administrators completed questionnaires from 1,061 schools in main assessment sample. 429 questionnaires from 457 schools in bridge samples. Schools selected during second stage of sampling plan.	
GENERAL VARIABLE DOMAINS PRESENT	-Academic performance in five subject areas (reading, writing, civics, U.S. history, geogrpahy). -Demographic/background characteristics. -Subject-specific background & attitude information which varied by subject area (e.g., instructional experiences, topics studied, amount of homework, enjoyment, personal & social use of skills, subject courses taken, etc.).	-Teacher characteristics. -Classroom curriculum and teaching methods. -Characteristics of students excluded from data collection (Excluded Student Questionnaire).	-School characteristics and policy information regarding administration, staffing patterns, special programs, subject requirements, and school resources.	
DISABILITY RELATED EXCLUSIONARY RULES AND PROCEDURES	Based on judgements of school staff, students with limited English proficiency, mild retardation (educable), or functional disability (temporary or permanent physical disability) were excluded. Exclusion rates varied by age/grade cohorts from 3.0 % to 8.3 % of originally selected students, with average exclusion rate of 5.7 %. Separate Excluded Student Questionnaire completed by school personnel for each excluded student. Separate special education schools excluded from target population.			
DISABILITY DEFINITIONS AND CATEGORIES	None used to describe final sample. Only disability related information gathered in reference to excluded students via Excluded Student Questionnaire which included information on ethnicity, reason for exclusion, functional grade levels, percent of mainstreaming and special education, areas of special education service, type of disability (multidisabled, mentally retarded, hard of hearing, deaf, speech-impaired, visually handicapped/blind, deaf/blind, emotionally disturbed, orthopedically impaired, learning disabled, other), degree of disability (mild, moderate, severe, profound).			
DISABILITY CHARACTERISTICS OF SAMPLE	No data reported.			

(NCEO/K. McGrew & A. Spiegel 2-17-92 Rev)

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The correspondence between the disability categories or terms used in each of the data collection programs and those used by the U.S. Department of Education in the annual report to Congress on the implementation of the Individuals with Disabilities Act (Department of Education, 1992) was compared. Only the correspondence between the categorical labels or terms was evaluated. No attempt was made to compare the correspondence between specific operational definitions or criteria.

Results

The correspondence between the 11 federal special education categories included in this analysis (the Autism and Traumatic Head Injury categories added in 1991 are not included) and the disability categories used in the 19 national data collection programs is summarized in Table 3. The results are organized by programs sponsored by educational (i.e., U. S. Department of Education) and non-educational agencies (i.e., other federal agencies). Tables listing the different disability-related category variables used to identify individuals in the different data collection programs are presented in Appendix A.

Analysis of this information revealed significant variability in the disability-related terminology used by educational and non-educational federal agencies, as well as within these agencies. The disability category for which there was the greatest similarity of terms across the largest number of data collection programs was speech impaired. Ten of the nineteen (52.6%) data collection programs made use of a single speech-related variable. Most of these programs (i.e., 9) were sponsored by the Department of Education. However, even within the programs sponsored by the Department of Education, there was variability. For example, no speech impairment variable was included in the NELS:88 program. A somewhat different approach was taken by the NHIS:89 survey, which used two different speech-related categories (i.e., stammering/stuttering and other speech impairment). Only one of the eight non-educational agencies (12.5%) included some form of speech-related category in its data collection program.

Given the educational nature of the learning disability category, it was not surprising to find a clear distinction between programs sponsored by the educational and non-educational agencies. None of the non-educational data collection programs used the term "learning disability." Nine of the eleven (81.8%) educational data collection programs included a single label indicating a learning disability. One educational data collection program (NELS:88) used a combined category (i.e., in a program for individuals with orthopedic or learning disabilities) that would make disaggregation of the results for only individuals with learning disabilities impossible. Across both types of agencies, only about one-half of the data collection programs (10 of 19; 52.6%) included a learning disability related variable.

For the three federal special education disability categories of mentally retarded, deaf-blind, and multihandicapped, either the federal category was used or the disability was not categorized at all. Seven of the 19 (36.8%) data collection programs used a term for individuals with mental retardation, and only five (26.3%) included the deaf-blind and multiple handicaps categories. In all but one instance (i.e., use of mentally retarded category in NHIS:89) all of the data sets that used these three federal categories were under the direction of the Department of Education.

Together with the previously presented results, all remaining analyses revealed that across data collection programs there was significant variability in the use of terms that corresponded to the federal categories of seriously emotionally disturbed, hard of hearing, deaf, visually handicapped, orthopedically impaired, and other health impaired. In each of these analyses, single and multiple category variables were found. When multiple categories would be appropriate, such as in the case of the separate federal special education categories of hard of hearing and deaf, only six data collection programs provided this option. Five of the six were under the direction of the Department of Education. However, sponsorship by the Department of Education did not insure

Table 3

Correspondence Between Federal Special Education Category and Disability Category Terms Used In Select National Data Collection Programs[a]

National Data Source[b]	Federal Special Education Category[c]									
Dept of Education	SI	LD	MR	SED	HHD	VH	DB	OI	OHI	MH
NLTS 87	*	*	*	*	*	*	*	*	*	*
NAEP 88	*	*	*	*	**	*	*	*	*	*
TSAP 90	*	*	*	*	**	*	*	*	*	*
NHESC 91	*	*	*	*	**	*	*	*	*	*
YALS 85	*	*			*	*		*	*	
NALS 92	*	*	*	*	*	*		*	***	
TS 87	*	*	*	*	**	*	*	*	*	*
BPS 90	*	*			*	*		*	*	
BB 93	*	*			*	*		*	*	
NELS 88		**			**			*		
NHES 91										
Other Agencies	SI	LD	MR	SED	HHD	VH	DB	OI	OHI	MH
NHIS 89	**		*	***	**	**		***		
NSFG 88										
NASHS 88										
YRBS90-91										
LSAY								*		
CPS										
NCS 86-89										
NHEFS 86					*			*		

[a]Table entries represent the number of category terms used in the national data source that correspond to the federal special education category (e.g., NHIS has two categories of speech impairment -- (1) stammering/stuttering, and (2) other speech impairment). The entry *** indicates 3 **or more** categories are used for the one federal category. Shaded cells indicate that **no** categories correspond to the federal special education category. Details on the information in this table are presented in Appendix A.

[b]Sources of data are listed in Table 2.

[c]Federal cateogries are as follows:

SI = speech impairment
LD = learning disability
MR = mental retardation
SED = serious emotional disorder
HHD = hard of hearing + deaf
VH = visual impairment
DB = deaf/blind
OI = orthopedic impairment
OHI = other health impairment
MH = multiple handicaps

the appropriate use of two categories in six of their other data collection programs. With the exception of NALS:92 in the case of the other health impaired, all instances where multiple categories were available that appeared to correspond to a single federal special education category were present exclusively in the NHIS:89 survey directed by the National Center for Health Statistics (NCHS).

The only non-educational data collection programs that included any variables that could be matched with the federal special education categories were LSAY, NHIS:89, and NHEFS:86. Such a finding is not surprising given that the non-educational data collection programs were designed to address predominately non-educational issues (e.g, health, crime, family growth). Although some of the non-educational data collection programs do not gather any disability-related information (NSFG:88; NASHS:88; NCS:86-89; YRBS:90-91), others (e.g., NHIS:89; NHEFS:86) do, but use a different conceptual framework such as the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) or the "functional limitation" or Nagi framework (Pope & Tarlov, 1991). Although there is some correspondence between terms used in these other disability conceptual frameworks and the federal special education categories, the correspondence is limited. Given that many of these non-educational data collection programs are some of the most inclusive national programs in terms of individuals with disabilities (McGrew, Thurlow et al., 1992), the lack of any disability-related category variables, or the limited correspondence with the federal special education disability category variables, results in a significant "lost opportunity" for the production of important policy-relevant information on this significant portion of the population.

Finally, it is important to note that the listing of a data collection program as including a term related to the federal special education categories does not mean that the disaggregation of the results by the disability category is possible. For example, the national and state NAEP programs (i.e., NAEP:88, TSAP:90) are listed as including many of the special education categories. However, this disability-related information was only collected for students who were excluded from the NAEP data collection activities. Disaggregation of the NAEP results for any students with disabilities that were not excluded is not possible. Thus, the relatively low summary percentages reported in the above analysis for the proportion of data collection programs that include variables similar to the federal special education related disability category variables paints a rosier picture than reality when data disaggregated by disability category is wanted from these programs.

Discussion

The results of this investigation indicate that there is significant variability among national data collection programs in the manner in which individuals with disabilities are identified. Notable differences were observed between data collection programs sponsored by educational and non-educational agencies. As would be expected when the federal special education categorical system was used as the basis for the analytical framework, data collection programs sponsored by the Department of Education contained the largest number of data elements displaying some correspondence to the federal special education categories. However, even within these programs, there was variability. Because of the related problem of significant exclusion of individuals with disabilities from these data collection programs (McGrew, Thurlow et al., 1992), there is little hope in extracting, on an ongoing basis, nationally representative policy-relevant information on the educational and quality of life outcomes for students with disabilities.

Taking a different educational orientation, the conclusions reached in this investigation echo recent conclusions of the Committee on a National Agenda for the Prevention of Disabilities (Pope & Tarlov, 1991). The Committee's conclusions were that:

> Despite its significance as a public health and social issue, disability has received little attention from epidemiologists and statisticians; consequently, surveillance of disabling conditions is inadequate in many ways. (p. 96)
>
> Much of the available information on people with disabling conditions has been collected piecemeal by many agencies, each with the aim of its own particular needs. (p. 97)

It must be recognized that many of the data collection programs reviewed here were not originally designed to provide answers to educational questions (e.g., data collection programs of the National Center for Health Statistics). These programs admittedly are burdened with many competing goals and objectives. In addition, a number of the programs only collect data on adult populations (e.g., NALS:92), and all information is obtained from the subjects themselves. The ability to obtain accurate self-report information on the formal special education categorical services a person may have received during school is problematic.

In an environment of limited resources for new and expensive large scale nationally representative data collection programs, it would be most practical and cost-effective to modify and use existing data collection programs to answer new and emerging questions. How individuals with disabilities are performing during and after their educational careers is an important public policy and research question that needs to be addressed now and in the future (Ysseldyke, Thurlow, Bruininks, Gilman, Deno, McGrew, & Shriner, 1992). Although specially designed national studies focused exclusively on the population of students with disabilities (i.e., National Longitudinal Transition Study of Special Education Students) provide valuable information, such special surveys are expensive, limited in coverage of outcome domains, provide no comparable data on students without disabilities, and are typically fixed duration studies that do not provide routine information as part of a recurring national information system.

Given the magnitude of federal and state support for educational programs for students with disabilities, support that reflects the valuing of this population in our society, it is time that this implied value is matched by the commitment of resources to address the numerous political and technical hurdles that must be overcome in order to be able to extract useful and routine information on the educational and quality of life outcomes for individuals with disabilities. It is no longer appropriate to consider most individuals with disabilities as "outliers" in our national data collection programs. The significant categorical exclusion of students with disabilities from many national educational data collection programs (McGrew, Thurlow et al., 1992), together with a lack of uniform disability identification terminology across programs, seriously hinders the ability to engage in meaningful discourse and answer important policy and research questions about individuals with disabilities in our society (Pope & Tarlov, 1991). Moreover, such a situation continues to perpetuate "the myth of inherent differences. It makes students with [disabilities] non-students and perhaps non-people" (NASDSE, 1988, p. 10).

A Step In The Right Direction

Under conditions of national importance, policy decisions should be made on the basis of information reflecting all students (Algozzine, 1992; Bruininks, Thurlow, & Ysseldyke, 1992; Ysseldyke, Algozzine, & Thurlow, 1992). Problems arise when different federal agencies or different programs within the same federal agency do different things. Variation in information about people with disabilities in national data sources creates variation in estimates of performance, prevalence, incidence, and contributions. Estimates from surveys and programs using different categories for classifying subgroups of individuals with disabilities create confusion for users of this information, including policy analysts and decision makers. Also, the lack of consistent disability-related category variables across national data bases makes it all but impossible to produce useful policy-relevant information from the secondary analyis of national data bases.

Toward the goal of improving the system for collecting and reporting information on national data bases by including students with disabilities, we offer the following suggestions:

1. A more uniform and standard disability variable system that parallels the federal special education categories should be used for educationally oriented national data collection programs, particularly those sponsored by the Department of Education. Such a system should be used not only to identify those individuals with disabilities who are excluded from these data collection programs, but should also be used to identify those individuals who do participate. The use of a standard system, together with increased efforts directed at decreasing the exclusion of individuals with disabilities and their increased participation through testing accommodations (McGrew, Thurlow et al., 1992), should increase the feasibility of disaggregating and reporting important outcome information.

2. Many non-educational data collection programs include numerous indicators that represent important domains in the NCEO conceptual model of outcomes for students with disabilities. For example, many of the data collection programs conducted by the National Center for Health Statistics (NCHS) include important indicators in the NCEO domains of physical health and social adjustment. More importantly, through the use of proxies (informed individuals who can answer questions) in many of the NCHS sponsored surveys, individuals with disabilities are excluded very infrequently (McGrew, Thurlow et al., 1992). Thus, many of these data collection programs are potentially rich sources of information on important outcomes for students with disabilities. However, as currently designed, this rich source of information is impossible to extract in a manner useful to the development of policy related to students with disabilities.

   It is recommended that a dialogue be initiated between representatives from the appropriate federal groups and agencies, both educational (e.g., NCES, NCEO, OSEP) and non-educational (e.g., NCHS, Census Bureau). The purpose of this dialogue would be to identify possible means by which uniform disability-related variables could be collected across agencies, particularly for the school-age portion of each data collection program. The feasibility of using the same special education categorical variable system recommended for the Department of Education (i.e., Recommendation # 1) should be examined. Alternatively, the feasibility of developing "cross-walk" procedures that would allow the different disability information collected by different agencies to be converted to the federal special education categories should be explored. This dialogue is necessary since it is important to know, for the general population as well as for students with disabilities, the extent to which individuals are using family planning, are engaging in high-risk health behaviors, are victims of crime, and are healthy. Systematic cooperative efforts among federal agencies are necessary to insure that important educational and quality of life information is available for <u>all</u> of the population.

3. Although the recommendation for a standard terminology system that parallels the federal special education categories would make policy research based on extant national data bases much easier, such an approach is not without problems. For example, local school records would be the most likely source that national data collection programs would turn to in attempts to identify students with disabilities who are selected for the data collection program's sample. Although most states use either the federal categories or modified versions of the categories, a number of states do not (Ysseldyke, 1987; Ysseldyke, Algozzine, & Thurlow, 1992). Procedures would need to be developed that would allow different state terms to be converted into the standard federal categorical framework. Research and discussion is needed to identify the possible problems and solutions to this issue.

In addition, much has been written within the special education literature about the problems in using a categorical system to organize the field of special education, with frequent calls for a noncategorical approach. The use of a standard categorical system for reporting national level policy reports may tend to contribute to many of the problems (e.g., a "hardening of the categories") mentioned by advocates of the noncategorical approach. Research and discussion is needed to determine what steps can be taken to minimze the potential negative effects of national categorically-based reports.

Finally, much has been written about the significant variability among states in the operationalization of the same federal disability categories, and the variability among professionals when implementing the same operational criteria (Ysseldyke, 1987; Ysseldyke, Algozzine, & Thurlow, 1992). These sources of variability can introduce unknown sources of error into any national statistical estimates that might be reported by different disability categories. Although accurately describing the disability population identified by current practice, research is needed to determine whether the classification of individuals included in the samples of national data collection programs can be made more uniform. Research and development activities are needed to explore the advantages and disadvantages of developing a small set of standard personal competency variables (e.g., academic, cognitive, adaptive, social, emotional, physical) that could be used in all data collection programs, the results of which then could be used to describe and operationally classify the sample respondents according to the federal special education categories.

4. In addition to the development of survey procedures to collect standard personal competence information for describing national samples (Recommendation # 3), it is also recommended that those individuals charged with the design of instruments used in national data collection programs include additional variables that would help to better describe those individuals who are included or excluded in such programs. An example of possible new variables that might be considered is presented in Appendix B.

Summary

Widespread exclusion of students with disabilities from national data collection programs, and extreme variability in the classifications that they assign to students with disabilities when they are included, represent a real failure to communicate. This lack of communication among national data collection programs on disability-related issues continues to have a significant impact on our ability to extract important information from existing data.

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Appendix A

Correspondence Between Federal Disability Categories and Categories Used in National Data Collection Programs

Table A1

Correspondence Between Federal Speech Impaired Special Education Category and Disability Categories Used in Select National Data Collection Programs

Type of category	Dept. of Education	Other Agencies
Single category Speech impaired or speech disability or speech limitations/disability or speech problem	NLTS:87, NAEP:88, TSAP:90, NHES:91 (Child), YALS:85, NALS:92, TS:87, BPS:90, B&B:93	
Two categories Stammering/stuttering, AND other speech impairment		NHIS:89
No category or unable to determine from documents	NELS:88, NHES:91 (adult)	NSFG:88, NASHS:88, YRBS:90-91, LSAY, CPS, NCS:86-89, NHEFS:86

Table A2

Correspondence Between Federal Specific Learning Disability Special Education Category and Disability Categories Used in Select National Data Collection Programs

Type of category	Dept. of Education	Other Agencies
Specific learning disability or learning disability	NLTS:87, NAEP:88, TSAP:90, NHES:91 (Child), YALS:85, NALS:92, TS:87, BPS:90, B&B:93	
Currently in a program for individuals with orthopedic or learning disabilities	NELS:88	
No category or unable to determine from documents	NHES:91 (adult)	NSFG:88, NASHS:88, YRBS:90-91, CPS, NHIS:89, NHEFS:86, NCS:86-89, LSAY

Table A3

Correspondence Between Federal Mentally Retarded Special Education Category and Disability Categories Used in Select National Data Collection Programs

Type of category	Dept. of Education	Other Agencies
Mentally Retarded	NLTS:87, NAEP:88, TSAP:90, NHES:91 (Child), NALS:92, TS:87	NHIS:89
No category or unable to determine from documents	NELS:88, NHES:91 (adult), YALS:85, BPS:90, B&B:93	NSFG:88, NASHS:88, YRBS:90-91, LSAY, CPS, NCS:86-89, NHEFS:86

Table A4

Correspondence Between Federal Seriously Emotionally Disturbed Special Education Category and Disability Categories Used in Select National Data Collection Programs

Type of category	Dept. of Education	Other Agencies
Single category		
Seriously emotionally disturbed	NLTS:87, NAEP:88, TSAP:90, NHES:91 (Child), TS:87	
Emotional disorder	NALS:92	
Multiple categories		NHIS:89
Variety of specific types of mental illness		
No category or unable to determine from documents	NELS:88, NHES:91 (adult), YALS:85, BPS:90, B&B:93	NSFG:88, NASHS:88, YRBS:90-91 ,CPS, NHEFS:86, NCS:86-89 LSAY

Table A5

Correspondence Between Federal Hard of Hearing and Deaf Special Education Categories and Disability Categories Used in Select National Data Collection Programs

Type of category	Dept. of Education	Other Agencies
Single category Hearing impaired or hearing impairment or hearing problem	NELS:88, BPS:90	NHEFS:86
Hearing problem/deafness	YALS:85, B&B:93	
Functional hearing impairment	NALS:92	
Two categories Hard of hearing or hearing impairment AND deaf	NLTS:87, NAEP:88, TSAP:90, NHES:91 (Child), TS:87	NHIS:89
No category or unable to determine from documents	NHES:91 (Adult)	NSFG:88, NASHS:88, YRBS:90-91, LSAY CPS, NCS:86-89

Table A6

Correspondence Between Federal Visually Handicapped Special Education Category and Disability Categories Used in Select National Data Collection Programs

Type of category	Dept. of Education	Other Agencies
Single category Visually Impaired/Blind	NLTS:87, NAEP:88, TSAP:90, NHES:91 (Child) TS:87	
Functional vision impairment	NALS:92	
Partially sighted or blind	B&B:93	
Eye trouble not corrected by glasses or visual impairment that cannot be corrected by glasses	YALS:85, BPS:90	
Two categories Blindness AND other visual impairment		NHIS:89
No category or unable to determine from documents	NELS:88, NHES:91 (adult)	NSFG:88, NASHS:88, YRBS:90-91, LSAY, CPS, NCS:86-89, NHEFS:86

Table A7

Correspondence Between Federal Deaf-Blind Special Education Category and Disability Categories Used in Select National Data Collection Programs

Type of category	Dept. of Education	Other Agencies
Deaf-Blind	NLTS:87, NAEP:88, TSAP:90, NHES:91 (Child), TS:87	
No category or unable to determine from documents	NELS:88, NHES:91 (adult), YALS:85, NALS:92, BPS:90, B&B:93	NSFG:88, NASHS:88, YRBS:90-91, CPS, NHIS:89, NHEFS:86, NCS:86-89, LSAY

Table A8

Correspondence Between Federal Orthopedically Impaired Special Education Category and Disability Categories Used in Select National Data Collection Programs

Type of category	Dept. of Education	Other Agencies
Single category		
Orthopedically Impaired or orthopedic disability/ limitation	NLTS:87, NAEP:88, TSAP:90, NHES:91 (Child), TS:87, B&B:93	
Orthopedic or mobility limitation	BPS:90	
Physical disability	YALS:85, NALS:92	
Physical illness and/ or disability		NHEFS:86
Currently in program for individuals with orthopedic or learning disability	NELS:88	
Participates in special class for educationally handicapped or for the physically handicapped		LSAY
Multiple categories		NHIS:89
Variety of specific physical or orthopedic categories		
No category or unable to determine from documents	NHES:91 (adult)	NSFG:88, NASHS:88, YRBS:90-91,CPS, NCS:86-89

Table A9

Correspondence Between Federal Other Health Impaired Special Education Category and Disability Categories Used in Select National Data Collection Programs

Type of category	Dept. of Education	Other Agencies
Single categories Other health impaired or other health related disability	NLTS:87, NAEP:88, TSAP:90, NHES:91 (Child), TS:87, B&B:93	
Long-term illness	YALS:85	
Multiple categories Long-term illness AND other health impairment	NALS:92	
No category or unable to determine from documents	NELS:88, NHES:91 (adult) BPS:90	NSFG:88, NASHS:88, YRBS:90-91 ,CPS, NHEFS:86, NCS:86-89 LSAY, NHIS:89

Table A10

Correspondence Between Federal Multihandicapped Special Education Category and Disability Categories Used in Select National Data Collection Programs

Type of category	Dept. of Education	Other Agencies
Multihandicapped or multidisabled	NLTS:87, NAEP:88, TSAP:90, NHES:91 (Child), TS:87	
No category or unable to determine from documents	NELS:88, NHES:91 (adult), YALS:85, NALS:92, BPS:90, B&B:93	NSFG:88, NASHS:88, YRBS:90-91, CPS, NHIS:89, NHEFS:86, NCS:86-89, LSAY

Appendix B

Example of New Variables to Be Considered

Information on Intellectual Functioning

(Possible Items)

1. Of the following choices, which best describes this student's level of intellectual functioning?

   A. Well above average (IQ above 115)
   B. Average (IQ 85 to 115)
   C. Below average (IQ 70-84)
   D. Mild retardation (IQ 36 to 51)
   E. Moderate retardation (IQ 36 to 51)
   F. Severe or profound retardation (IQ 35 or below)
   G. Don't know, unable to provide estimate

2. When providing the information on this student's level of intellectual functioning, which of the following was the basis for your response?

   A. Most recent standardized intelligence test score
   B. Professional estimate, not based on standardized intelligence test scores
   C. Combination of standardized intelligence test score and professional judgment
   D. Unable to provide an estimate

Information on Personal Functioning

(Possible Items -- Items 1-6 are from the ICAP (Inventory for Client and Agency Planning), authored by Bruininks, Hill, Weatherman, and Woodcock, and published by The Riverside Publishing Company, copyright 1986. The items are reproduced here with permission of the Riverside Publishing Company.

1. Of the following choices, which best describes this student's primary means of communication or expression? (circle one)
   1 None
   2 Gestures
   3 Speaks
   4 Sign language or finger spelling
   5 Communication board or device
   6 Don't know

2. Of the following choices, which best describes this student's vision? (circle one)
   1 Sees well (may wear glasses)
   2 Vision problems limit reading or travel (may wear glasses)
   3 Little or no useful vision (even with glasses)
   4 Don't know

3. Of the following choices, which best describes this student's hearing? (circle one)
   1 Hears normal voices (may use hearing aid)
   2 Hears only loud voices (may use hearing aid)
   3 Little or no useful hearing (even with hearing aid)
   4 Don't know

4. Of the following choices, which best describes this student's general health? (circle one)
   1 Health results in no limitation in daily activities
   2 Health results in few or slight limitations in daily activities
   3 Health results in many or significant limitations in daily activities
   4 Don't know

5. Of the following choices, which best describes this student's use of his/her arms and hands? (circle one)
   1 Normal, or no limitations in daily activities
   2 Some daily activities limited
   3 Most daily activities limited
   4 Don't know

6. Of the following choices, which best describes this student's mobility or movement throughout the school building? (circle one)
   1 Walks by self with no assistive devices (cane, walker, crutches, etc.)
   2 Walks by self with assistive devices (cane, walker, crutches, etc.)
   3 Usually in a wheelchair
   4 Limited or confined to specially designed chair or bed most of the day
   5 Limited or confined to specially designed chair or bed for entire day
   6 Don't know

7. Of the following choices, which best describes this student's behavior in typical educational and social settings? (circle one)
   1 Normal behavior, with no limitations in daily activities
   2 Minor behavior problems, with no limitations in daily activities
   3 Moderate behavior problems, with some limitations in daily activities
   4 Severe behavior problems, with many limitations in daily activities
   5 Don't know